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Chapter 1

General Introduction

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“Health for all in the 21st century” is a 1998 World Health Organization (WHO) declaration that most countries are striving to ensure for their citizens (1). This means that all populations, including patients with chronic diseases, receive the quality and safe health services they need. Epidemiological transition is changing the pattern of health and disease in the world, and certainly in low- and middle-income countries (LMICs). The transition is described as a shift in the pattern of mortality and disease such that acute infectious diseases are slowly being replaced by degenerative and lifestyle diseases as the prominent causes of disease and death. This shift is closely linked to the increased modernization, industrialization and urbanization that have led to changing lifestyles and increasing life expectancy (2, 3). Because of this transition, LMICs are experiencing an increasing burden of non-communicable diseases (NCDs), while the burden of communicable and deficiency diseases persists, causing what is known as the ‘double burden’ of diseases (3). NCDs are currently the biggest killers in the world, having caused 38 million deaths (68% of all global mortality) and contributed to a substantial loss of disability-adjusted life years (DALYs) in 2012 (4, 5). LMICs bear the brunt of NCDs, as 80% of the world’s NCD-related deaths (4) and two thirds of DALYs lost worldwide are in these countries (6). Yet these countries are also shouldering most of the burden of the 5.6 million deaths and 166 million DALYs lost annually to HIV, malaria and tuberculosis globally (7). The sub-Saharan African region, for instance, had 25.8 million people living with HIV and a reported 790,000 HIV-related deaths in 2014, which represented 70% of prevalence and 66% of deaths globally (8).

The four major NCDs that have received much attention due to their association with premature deaths (of persons aged 30–70 years) are cardiovascular diseases, cancers, type 2 diabetes (henceforth referred to as diabetes) and chronic obstructive respiratory diseases (9). Incidentally, all of these are chronic diseases. According to the WHO, a chronic disease is one that has a long duration and progresses slowly (10). The scale-up of antiretroviral therapy (ART) has meant that HIV patients now survive for longer on treatment that requires regular monitoring and which essentially transforms treated HIV into a chronic disease (11).

Health systems are the channel for delivering health care services, including those for chronic diseases. In LMICs, these systems are operating with very limited resources in terms of financing, health workforce and governance (12). In addition, the literature describes these systems as having been designed for the management of acute diseases (13). However, these systems are also dealing with chronic diseases, which place different and extra demands — also on patients and families — compared to acute diseases. The demands on the health systems include the need for planned care that anticipates patients’ needs and is continuous across time, settings and different providers (14). These increased demands on the health system have also been demonstrated by a 2014 multi-country study, which estimated that diabetes patients in LMICs used five times more medication, were admitted for 13 times

more days and made seven times more outpatient visits than non-diabetes patients living near them (15). The burden of chronic diseases on the health system is further worsened by the fact that chronic diseases are increasingly occurring in parallel. This is referred to as chronic multi-morbidity (more than one chronic disease in one patient) and is known to increase the complexity of the management of the co-existing conditions (16, 17).

It has been suggested that it is more economically sensible to prevent — rather than treat — chronic diseases at all levels from individual to global (18-21). Although this is true, there have so far been very limited NCD prevention efforts in LMICs. Additionally, NCD prevention interventions take time to yield results, while the incidence of NCDs continues (22), making it necessary to also focus on care and treatment of those already afflicted. However, health services required to diagnose and treat NCDs are not fully formed in LMICs. For example, a 2011 review estimated that 85% of diabetes patients in sub-Saharan Africa were undiagnosed (23), indicating a weakness of health systems in these countries to identify and care for them. Focusing on care and treatment is also mandated by the large NCD-related morbidity and mortality burden among the most economically productive populations in LMICs (24, 25), which adversely affects both national development initiatives as well as household-level economic standing (26). It is also especially important to focus on care and treatment of uncomplicated disease to prevent the development of complications, because the management of uncomplicated NCDs costs a lot less than managing complicated ones (27). Global-level health policies also support care and treatment as one focus area in the efforts to control NCDs. For instance, the global action plan for the prevention and control of NCDs 2013–2020 has as one of its targets to reduce the relative risk of premature death from the four major NCDs, and as one of its objectives, to strengthen and orient health systems to be able to prevent and control NCDs (28).

Regardless of the aetiology of the chronic disease, the main aim of care and treatment is to achieve disease control and to limit the development of complications (11, 29). In most LMICs, the situation of care and treatment for NCDs is not well documented. However, the few existing studies indicate that the health systems in LMICs are unprepared for NCD care and treatment; that they are weak, fragmented and thus incapable of effectively dealing with chronic diseases (9, 30). A study of quality and outcomes of diabetes care in six African countries concluded that care and treatment services were centralized in higher-level facilities and that the quality of care was sub-standard, which led to experiences of diabetes complications (31). However, in these LMICs, care and treatment for HIV/AIDS is well established and provides a chronic disease care and treatment model that is working, although not perfectly, in rural primary care settings. In LMICs, HIV care and treatment has been scaled up to primary care facilities where ART can be initiated and monitored (32). There is an increase in the number of patients receiving ART, and HIV-related morbidity and mortality have decreased in these countries (33). A review indicated that about 84% of HIV

patients who initiated ART in LMICs attained viral load control after 12 months of treatment (34). However, care and treatment of HIV in LMICs faces substantial challenges, including unsustainable financing. Many eligible patients for ART are still unreached, up to 10% of patients initiating ART die within 12 months, and retention of patients in care and treatment is still unsatisfactory (33).

As one of the LMICs, Tanzania is also experiencing the double burden of disease. The increasing prevalence of NCDs is exemplified by the rising prevalence of type 2 diabetes. In the 1980s, this prevalence was at 0.8% in urban and 0.9% in rural areas, rising to 4.0% in urban and 1.3% in rural areas in 2000 (35), and estimated in a national survey at 9.1% in 2012 (36). Furthermore, NCDs accounted for 31% of deaths in the country in 2014 (37). As an example of a persisting communicable disease, the HIV prevalence is still at the level of a generalized epidemic in Tanzania despite having decreased from its peak of 7% in 2004 to 5.1% in 2012. (38). These changes in health and disease patterns are also affecting the rural areas of Tanzania, as shown by the rising prevalence of type 2 diabetes in rural areas from 0.9% in the 1980s to 1.3% in 2000 (35) and the high HIV/AIDS prevalence in rural Tanzania of 4.5% in 2012 (38). There is also evidence of prevailing common NCD risk factors — i.e. poor dietary intake, reduced physical activity, alcohol abuse and tobacco use — in rural Tanzania (39, 40). The occurrence of chronic multi-morbidities has also been documented in Tanzania. Co-morbidities of tuberculosis and diabetes (41) and of HIV and hypertensive heart diseases (40, 42) have been demonstrated. Furthermore, in a rural district, stroke has been associated with HIV and diabetes (43).

The question then arises of how health systems in Tanzania and other LMICs can deal with the increasing burden of chronic diseases whose requirements are different and whose presentations are increasing in complexity due to chronic multi-morbidity, given their resource-limited circumstances.

In most countries, those likely to die from chronic diseases are people with low socio-economic status and those who live in poor or marginalized communities (44). Multi-morbidities are also disproportionately affecting the poorest populations (9). In Tanzania over 70% of the population resides in rural areas (45), and about 90% of Tanzanians living in poverty also reside in rural areas (46, 47). The health system's main problems — such as the shortage of health workers, health service financing weaknesses (48), problems with the availability of health services and unreliable supplies of health care commodities and medications — are worse in rural areas (48-50). To ensure health for all in Tanzania, rural communities, including rural chronic disease patients, must be included in the search for, the design and implementation of health care systems that can meet their needs in their circumstances. Despite the resource limitations in rural areas, primary care management of NCDs is happening, but little is known about the current NCD service delivery in these areas. Learning from the successes and failures

of the current delivery of these services can contribute to and expand the evidence base for NCD service provision in rural areas in LMICs.

The thesis addresses this knowledge gap and **aims to investigate service provision and use for HIV and diabetes in rural areas in Tanzania in order to inform the design of chronic care services.**

Background

1.1 Health care system in Tanzania

The United Republic of Tanzania is a union of mainland Tanzania and Zanzibar, which is a semi-autonomous entity. Health is one of the sectors that is not administered under the union (51). This thesis is based in mainland Tanzania. Tanzania is located in East Africa. In 2012, it had a population of 43,625,354 people (52). At the time of the study, mainland Tanzania was administratively divided into 25 regions and 154 districts (52), and over 70% of the population lived in rural areas (45).

1.2 Health status and government strategies

The health status of the country is summarized in Table 1.1, using selected health indicators (35, 36, 50-52).

Table 1.1. Selected health indicators for Tanzania and the WHO Africa region

Indicator	Tanzania	Source of Tanzanian data	Africa	Source of African data
Life expectancy at birth m/f (years)	61/65	WHO 2015	60	WHO_Africa 2011
Crude mortality rate per 1,000 population	9.3	NBS ^μ 2012	10.1	WHO_Africa 2012
Under-5 mortality rate (per 1,000 live births)	81	DHS [#] 2010	95	WHO_Africa 2012
Maternal mortality ratio (deaths per 10,000 live births)	454	DHS 2010	560	WHO_GHO*
HIV/AIDS prevalence (15–49 years)	5.1%	THMIS ^β 2012	4.6%	WHO_Africa
Diabetes mellitus prevalence (25–64 years)	9.1%	STEPS [¥] 2012	4.9%	IDF ^Φ Atlas 6 th edition
[£] Adult mortality per 1,000 population	279	WHO Africa	306	WHO_Africa
Infant mortality rate (per 1,000 live births)	51	DHS 2010	-	-

*Global Health Observatory on sexual and reproductive health

[£]Adult mortality = Probability of a 15-year-old dying before 60 years of age

[#]Demographic and health survey

^μNational Bureau of statistics

^βTanzania HIV and Malaria indicator survey

[¥]WHO STEPwise survey of NCD risk factors

^ΦInternational Diabetes Federation

Tanzania's health indicators are comparing well to those of other African countries, despite being one of the poorest countries in the world. The health status of its population has continued to improve in recent years. Between 2000 and 2012, life expectancy at birth for both sexes increased by 11 years, compared to an average increase in the WHO Africa region of seven years. Similarly, under-five child mortality declined from 167/1,000 in 1990 to 81/1,000 in 2010, and the WHO estimated that it was 57/1,000 in 2013 (53) (54). Although HIV prevalence is still high, at 5.1% in 2012, it is a remarkable decline from 7% in 2003/04 (38). NCDs and their risk factors are common in Tanzania, as a 2012 national survey revealed (36).

The health sector is guided by a strategic plan whose current version was approved in 2015 for the period 2015–2020. The main strategic objectives of Tanzania's Ministry of Health and Social Welfare (MoHSW) have to do with quality improvement of primary health care services, including a gradual increase in diagnostic and therapeutic capacities for NCDs; improving equitable access to services; achieving active community partnerships; and achieving a higher rate of return on investment in health interventions by addressing the social determinants of health (55). Below, the health system in Tanzania is briefly presented according to the six elements of a health system according to the WHO (56): administration or governance, service organization, financing, the health workforce, health information and the supplies management system.

1.4 Public administration in Tanzania

In Tanzania, public administration is decentralized through the devolution of powers to lower geographical units. This means that the planning, implementation and management of development activities for all sectors, including health, is happening at lower administrative levels. The mandate to decentralize powers came through the Local Government Act of 1982, and the process was accelerated by the health sector reforms of 1994. The main aim of decentralization is to ensure good governance and democratic participation. Whereas district councils are responsible for the implementation of decentralized functions for all sectors within the district (57), the council health management teams (CHMTs), working under the district councils, are specifically in charge of managing health services in the district. The district medical officer who heads the CHMT represents the health sector on the district council. CHMTs plan, deliver and oversee health services in the district, making them the unit of decentralization (55, 58). Regional health management teams are responsible for overseeing the work of regional referral hospitals and providing technical and administrative support to the CHMTs within their region. Centrally, the MoHSW provides technical support, while the Prime Minister's Office provides administrative support to the regional and district health teams. International relations, budgeting and policy formulation are still handled centrally (55, 58). In practice though, there are challenges of decentralization in the health sector, which include poor participation of communities in planning for health, insufficient fund allocations, delayed disbursement of allocated funds from central government and interference by politicians in decision-making in district councils (59).

1.6 Health service organization

Tanzania's health services are provided through 6,889 health facilities (in 2013), 26% of which are privately owned (57). Table 1.2 shows the distribution of these facilities according to their level and ownership. Although village health posts are listed as the lowest level of health facility in Tanzania, data about them could not be found. Private health facilities are organized under three umbrellas that represent their interests: the Association of Private Health Facilities in Tanzania, the Christian Social Services Commission and the National Muslim Council of Tanzania (BAKWATA) (60).

Table 1.2. Distribution of health facilities in Tanzania according to ownership (2013)

Level of facility	Private (%)	Government (%)	Total
Dispensary	1,444 (24%)	4,469 (76%)	5,913
Health centre	222 (31%)	489 (69%)	711
Hospital*	140 (55%)	114 (45%)	254
Total facilities in 2013	1,806 (26%)	5,072 (74%)	6,878

*Hospital as a level of health facility above health centre, including district, regional and referral hospitals

Source: MoHSW, HRH report 2013/14

Public health services are provided following a hierarchy from the grass-roots level of the village health posts up to referral or specialist hospitals. The higher levels are supposed to provide increasingly sophisticated and well-defined services (55). Table 1.3 presents this hierarchy.

Table 1.3. Levels of facilities and services they should provide

Administrative level	Level and target population	Services provided	Cadres of service providers
	Treatment abroad	For services not available in Tanzania. Patients are referred abroad on government subsidy.	-
Zone and national	Referral/ specialist hospitals	Comprehensive specialist services Teaching and research	Specialist doctors Registered nurses
Region	Regional hospitals	Services offered at district hospitals plus: Specialist services in various fields such as psychiatry, ear, nose and throat (ENT), ophthalmology, dentistry, intensive care, gynaecology and obstetrics, radiology, pathology, higher-level surgical and medical services	Specialist doctors Medical doctors Registered nurses

District	District hospitals	Services offered at health centres plus: Other general services In-service training Consultation and research into community-based health care programmes	Medical doctors serve in some of the district hospitals; Many are run by assistant medical officers (AMOs); supported by clinical officers and enrolled and registered nurses
Division	Health centre	Preventive, promotive, outpatient, curative, maternity,	Clinical officers Aided by enrolled
	50,000 people	inpatient services, emergency surgery and blood transfusion and laboratory services	nurses
Ward	Dispensary 6,000 to 10,000 people	Preventive, promotive, outpatient, curative and outreach care	Clinical assistants; Assisted by an enrolled nurse
Village	Village health posts <5,000 people	Community-based preventive and promotive health services	Village health workers

Village health workers = staff who have undergone a short training are expected to run a village health post

Enrolled nurse = secondary school graduate with two years of training in nursing care of minor ailment:

Registered nurse = secondary school graduate with three or more years in nursing school and legally authorized (registered) to practise after examination by a state board of nurse examiners

Clinical assistant = secondary school graduate with two years of training in anatomy, physiology, hygiene, diagnostic methods, and treatment of common illnesses

Clinical officer = secondary school graduate with three years of basic clinical training

AMO = clinical officers with a further two years of clinical training

Source: Adapted from MoHSW HRH report 2014

Although primary care is supposed to be provided at the village health posts, dispensaries and health centres, the hierarchy of services does not always function as expected, and higher-level facilities often offer primary care services (61). The village health posts are also not consistently present in all districts. Most district hospitals are government-owned. However, a few districts rely on hospitals owned by faith-based organization that are designated as district hospitals (61).

1.6 Financing, health workforce, information systems and supplies management

One objective of Tanzania's health financing policy is "to ensure that sufficient resources exist to enable health care providers to deliver a basic package of high-quality health care services" (62). The total budgetary allocation for health in the financial year 2013/14 was Tanzanian shillings 1,498 billion (USD 863 million at end of 2014), which at 8.2% of the whole budget is still below the 15% agreed in the Abuja commitment (63). After the introduction of user fees in 1994, a waiver policy was designed to ensure that vulnerable groups, such as children, elderly and chronic disease patients, can access essential health services (64). However, evaluations of this policy have shown that it is not yielding the desired effect of protecting vulnerable populations from catastrophic expenditure on health services (65). The ineffectiveness of the policy is further illustrated by a study that found that households with a chronic disease patient spend on average 22% more money on health care than those without such a patient (66). The Tanzanian government is exploring innovative and comprehensive health financing mechanisms, including the establishment of a single national health insurer, to realize its commitment to universal health care, and the establishment of the AIDS Trust Fund, a local fund for HIV/AIDS care and treatment to ensure sustainability of financing for HIV care and treatment (67). Both these require significant reforms in legislation, budgeting and coordination in implementation and so are likely to take some years before they are realized.

The health system has only an estimated 58% of the health workforce (professional and non-professional) needed, so the shortage in Tanzania is still critical, and more severe in rural areas (57, 68). Primary care facilities bear the brunt of this shortage compared to higher-level health facilities. In 2013, for instance, dispensaries had a shortage of 70.6% (37,597 workers), followed by health centres at 62.5% (14,224 workers) and then district hospitals at 30.1% (20,948 workers) (57). Efforts to build the capacity of health workers to better provide services for NCDs have been ongoing, albeit intermittently, focused on a few regions of the country and largely driven by disease interest groups (35).

The health information system (HIS) comprises an array of sub-systems, including the health management information system (HMIS), which refers to facility-based health records, and the disease surveillance systems, which include the chronic diseases surveillance system that only tracks HIV, tuberculosis and leprosy (69). A 2007 assessment of the HMIS found that parallel systems were common in the form of HMIS complementary data collection tools created to track programme-specific indicators such as for HIV and tuberculosis (69). The HIS was found to have some strengths, summarized as the comprehensiveness of data collected and the government and stakeholder support for the system. However, two major weaknesses noted were the frustration of the mainstream HMIS by allowing parallel sub-systems, and the failure to accommodate current changes in the health and diseases patterns, which partly encourages the parallel systems (69). Since the 2007 assessment, Tanzania has made some strides in improving the HMIS by adopting the district health information

system 2 (DHIS2) HMIS nationally (70). The effects of this system on the problems identified in the 2007 assessment are yet to be evaluated. At facility level, inefficiencies in the HMIS have been associated with the lengthy and laborious nature of the system, lack of training, inactive supervision, and staff workload which jeopardizes the quality of the information collected (71). In Tanzania's public facilities, the same HMIS within facilities is also recording care and treatment information for NCDs.

Regarding supply chain management, a 2012 review showed that essential medicines were not available in health facilities, including some NCD-related medications, maternal and child health products, family planning products and malaria drugs, while the availability of antiretroviral medication (ARVs) was much better (72). The review further found that funding for non-HIV medicines and supplies was inadequate. The Medical Stores Department (MSD) is the unit within the MoHSW that is responsible for the procurement, storage and distribution of health-related equipment, commodities and medication (72). The review found that not all products listed in the essential medicines list are routinely stocked by the MSD. Leadership and accountability mechanisms at different levels from the community to the ministry were unclear. Furthermore, supply chain management advisors provided more critical oversight and management of HIV-related drugs (ARVs) and laboratory items within the zones compared to the management of other non-HIV-related products (72). NCD supplies and medication are part of the non-HIV-related medicines and supplies.

1.7 HIV care and treatment in Tanzania

In section 1.6, the vertical nature of the HIV care and treatment programme was alluded to through the existence of almost separate sub-systems for supply chain management and information. The whole HIV programme is dependent on international donors for 95% of its funding (73). At health facilities, room(s) or buildings have been designated as being for HIV services only. At other facilities, designated health workers only provide HIV services. In November 2004, Tanzania started providing HIV care and treatment in the public health service, with 96 health facilities at district level or above involved. At the end of 2007, a decision was made to include primary care level facilities — i.e. dispensaries and health centres — in the expansion plan, necessitating the training of 1,333 health workers from 500 primary care facilities by the end of 2008 (74). The successes of this programme include improved access to HIV care and treatment services for patients even in rural areas and the achievement of favourable ARV adherence rates, with 77% of patients who remain in care achieving adequate levels of adherence, according to a 2006 meta-analysis (75). As stated earlier, the aim of care and treatment for chronic diseases is to achieve control of the disease progression and to minimize disease complications (11, 29). HIV control, measured by increasing or high CD4 count, has in Tanzania been associated with a patient's adherence to ARVs, not changing clinics and having a treatment supporter (76). This and other studies show that chronic disease control is related to how well the patient adheres to care

practices and also to the quality and organization of the care delivered (77, 78). Despite the progress made in providing HIV care and treatment at primary care level, the programme faces challenges which include the high rates of undiagnosed patients (at about 30%) and weaknesses of retaining diagnosed HIV patients in the continuum of care (79).

1.8 Diabetes care and treatment in Tanzania

The care and treatment of diabetes in Tanzania falls under the NCD unit of the MoHSW. The NCD unit, unlike the HIV or malaria programmes, does not receive any ring-fenced donor funds for its activities. It does receive some funds from the MoHSW. However, 85% of these funds are designated for the Ocean Road Cancer Institute (a specialist hospital), and the remainder is shared between tobacco control activities and the NCD programme's running costs (38, 80). Further efforts to improve care and treatment for diabetes are at the policy level, with the drafting of the Action Plan for the Prevention and Control of Non-Communicable Diseases in Tanzania 2015–2020, which includes strategic objectives to integrate NCD services into existing health care services up to the community level and to improve the efficiency, coverage and quality of NCD services at all levels (81). At the implementation level, diabetes care and treatment services are still centralized in hospital-level facilities, with government-owned facilities being less likely to offer the services than those owned by other authorities (82). Blood sugar control within a predefined range has been correlated with the control of the disease and is associated with reduced experience of complications (29). The prevalence of patients with poorly controlled blood sugar or with complications can, therefore, be used to infer both the quality of services provided and how well patients adhere to care practices. In Tanzania, for example, over 80% of diabetes patients registered for treatment in one region have been found with a form of chronic kidney disease, a complication of diabetes, and most of them were not aware that they had the complication (83, 84, 85). In general, diabetes services in Tanzania are under-funded and are centralized at higher-level facilities, and unfavourable patient outcomes are prevalent.

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